

Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis

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Objective: To determine whether first physician seen and symptoms beginning in adolescence have an impact on the diagnostic experience of endometriosis.

Design: Cross-sectional study of self-reported survey data.

Setting: Academic research.

Patient(s): Four thousand three hundred thirty-four Endometriosis Association Survey respondents reporting surgical diagnosis of endometriosis.

Intervention(s): None.

Main Outcome Measure(s): Specialty of first physician seen, timing of onset of symptoms, time to seeking medical care and to diagnosis, number of physicians seen, and satisfaction with care.

Result(s): Almost all respondents reported pelvic pain. Fifty percent first saw a gynecologist and 45% saw a generalist for symptoms related to endometriosis. Two thirds reported symptoms beginning during adolescence; they waited longer to seek medical care than adults did. Those seeing a generalist first took longest to get diagnosed; those seeing a gynecologist first saw fewer physicians. Sometime before diagnosis, 63% were told nothing was wrong with them.

Conclusion(s): Women and girls who reported seeing a gynecologist first for symptoms related to endometriosis were more likely to have a shorter time to diagnosis, to see fewer physicians, and to report a better experience overall with their physicians. The majority reported symptoms beginning during adolescence, also reporting a longer time and worse experience while obtaining a diagnosis. (Fertil Steril® 2008; ■:■–■. ©2008 by American Society for Reproductive Medicine.)

Key Words: Endometriosis, diagnosis, physician specialty, adolescence, pelvic pain, symptoms, health care

Endometriosis, the presence of endometrial tissue growing outside of the uterus, has been estimated to affect 10% to 15% of reproductive-age women (1, 2) and 70% of women with chronic pelvic pain (3, 4). Symptoms related to endometriosis vary but most commonly include chronic pelvic pain and subfertility. The time from the onset of symptoms to diagnosis is disturbingly long, and although some report that it

is on the decline (5), others indicate that it can last up to 10 to 12 years in the United States (6, 7). There are many possible reasons for the long diagnostic experience, including the variety of pain symptoms (8), which may be related in part to coexisting conditions (6, 9), whether or not subfertility is present (5, 10), and that surgery has been the gold standard for diagnosis. Ballard et al. recently reported that pain symptoms beginning in adolescence and suppression of symptoms with hormones, as well as a perception that the patient is not actually ill, also could lengthen the time to diagnosis (11). Women who first experience symptoms at a younger age typically have a longer time to diagnosis compared with those who experience their first symptoms later in life (5). Fortunately, the long time to diagnosis for adolescents is not universal (12, 13).

In a study of both gynecologists and generalists at a women's health clinic, Lentz et al. found that gynecologists were nearly nine times as likely to diagnose pelvic pain and

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more than eight times more likely to diagnose dysmenorrhea than internists (14). It has also been reported that adult women with pain and an eventual diagnosis of endometriosis have the largest number of diagnoses and highest rates of referrals in the United Kingdom system (15). Although these studies may support the importance of physician specialty for the diagnosis of endometriosis, the first physician a woman sees, and consequently the initial diagnostic label she receives, may play a larger role.

This study, therefore, investigates whether the first physician a woman sees for symptoms related to endometriosis affects her reported diagnostic experience. We hypothesized that women who report having seen an obstetrician/gynecologist first would report a shorter time to diagnosis, seeing fewer physicians, and overall greater satisfaction with medical care. We also investigated how onset of endometriosis-related symptoms during adolescence affects the diagnostic experience of women with endometriosis.

MATERIALS AND METHODS

Information was gathered from a questionnaire developed by the Endometriosis Association (Milwaukee, WI) and mailed in 1998 to approximately 10,000 of its North American members. The 4,745 respondent questionnaires were entered into the Clinical Trials Database at the National Institute of Child Health and Human Development (Bethesda, MD). To ensure confidentiality, all questionnaires were made anonymous and deidentified. The study was approved as exempt from review by the Investigational Review Board of the Office of Human Subjects Research at the National Institutes of Health.

The 10-page survey included questions on demographic characteristics; symptoms related to endometriosis including pain, infertility, and bleeding; and urinary, bowel, and systemic symptoms. Pain symptoms were grouped into three categories: pain at the time of menstruation, at ovulation, or at other times in the menstrual cycle. Reported bleeding symptoms included heavy bleeding and premenstrual spotting. Urinary symptoms included only pain with urination, and bowel symptoms were defined as the presence of abdominal pain, rectal pain, diarrhea, abdominal bloating, painful bowel movements, or other intestinal upset at the time of menses. Nausea or stomach upset and dizziness or headaches at time of menses were characterized as systemic symptoms.

Respondents reported the order and specialty of the first four physicians they saw for endometriosis-related symptoms by selecting from a list of specialists or indicating other types of physicians that were not listed. Independent of the types of physicians seen, they also reported the total number of physicians seen before diagnosis and provided qualitative information about satisfaction with their physicians overall, taking everything into account. How seriously patients reported they were taken by physicians and how helpful physicians had been were grouped into two categories: not taken seriously and physician not helpful, or taken seriously and physician helpful.

Age at onset of pelvic symptoms was gathered in 5-year categories ranging from “under 15” years to “45 years or older.” Respondents reported how long they waited to seek medical attention after experiencing endometriosis-related symptoms, the time it took for diagnosis from seeking medical attention, and the method and year of diagnosis with endometriosis.

Those reporting surgical diagnosis of endometriosis were classified into the following three groups of first physician seen: gynecologist, generalist, and other. Obstetrician/gynecologists ($n = 2141$) and reproductive endocrinologists ($n = 39$) were classified as gynecologists. Generalist was defined as a general/family practitioner ($n = 1897$), internist ($n = 36$), or pediatrician ($n = 22$). All other specialists, including gastroenterologists ($n = 46$), emergency department physicians ($n = 28$), urologists ($n = 23$), surgeons ($n = 9$), psychiatrists/psychologists ($n = 5$), rheumatologists ($n = 4$), neurologists ($n = 1$), nurse/nurse practitioner/physician’s assistants ($n = 4$), and all other nonspecified specialists ($n = 79$) were grouped into the “other” category.

Those selecting onset of pelvic symptoms as “under 15” and “15–19” years old were categorized as adolescents, and all others (age 20–45+ years) were classified as adults at onset of symptoms. Age at diagnosis was determined from year of birth and year of diagnosis.

Data Analysis

Subject characteristics were described by simple descriptive statistics and frequency distributions. Categorical data were compared by χ^2 tests, and continuous data were compared with use of generalized linear models for unbalanced designs in analysis of variance (ANOVA). Least-squares means adjusting for main effects were computed and are reported, unless otherwise indicated. Comparisons of continuous data between adolescent and adult age of onset of symptoms were compared by using t -tests. A χ^2 test for trend was performed when appropriate. Post-hoc comparisons were adjusted for multiple comparisons with use of the Bonferroni correction method.

Demographic characteristics, such as race, age at time of survey completion, education, and income, which may influence the type of physician seen first, were analyzed for differences, and subsequent analyses were adjusted for these potential confounders. Analyses involving the comparison of adolescent versus adult onset of symptoms were first conducted for differences in age at time of survey completion, then adjusted if appropriate. Logistic regression modeling or generalized linear modeling in ANOVA was used to adjust for potential confounders for categorical and continuous outcomes, respectively. Because reports of symptoms related to endometriosis represented lifetime prevalence rather than specifically relating to their diagnostic experience, analyses on symptoms were unadjusted.

The data met the assumption of normal distribution for the described statistical tests. Analyses were considered

statistically significant if the P value was $\leq .05$, unless the Bonferroni correction applied, or if the odds ratio (OR) was less than or greater than 1.0 with its 95% confidence interval (CI) excluding 1.0. Data were analyzed with use of SAS system software (version 9.1; SAS Institute, Cary, NC).

RESULTS

Study Population

Of the 4,746 women and girls who responded to the questionnaire, 4,359 (91.9%) reported surgically diagnosed endometriosis by either laparoscopy or laparotomy. Analyses were restricted to 4,334 (91.3%) subjects who also provided a response to the type of first physician seen. Fifty percent of respondents first saw a gynecologist, 45% saw a generalist, and 5% saw another specialist first (Table 1). Two thirds (67.1%) of respondents reported having symptoms related to endometriosis during adolescence (Table 2).

The respondents were primarily white, with 6% identifying themselves as Asian, black, Hispanic, Native American, or other. Those seeing a gynecologist first were slightly older than either the generalist or other specialist groups (Table 1). The majority of respondents (89.6%) had at least some college education, and more than half (63.6%) had a combined family income of \$50,000 or more a year, with those seeing a gynecologist first more likely to have reported higher incomes ($P < .0001$). Because of the statistically significant differences in age and family income, potentially influencing type of physician seen first, analyses involving the diagnostic experience were adjusted for these variables. Similarly, those with adolescent onset of symptoms were younger at the time of survey completion than those with adult onset (35.3 ± 0.10 vs. 37.8 ± 0.20 years, $P < .0001$); therefore, analyses comparing these two subsets were adjusted for age.

Symptoms Attributed to Endometriosis

Table 1 presents detailed results of reported symptoms. Nearly all of the respondents (98.4%) reported pelvic pain. Eighty-four percent had menstrual pain, of whom 67% also reported ovulatory and nonmenstrual pain. Women and girls seeing a generalist first were more likely to report the lifetime presence of all three pain types ($P < .0001$). More than half (58.5%) had heavy bleeding. The majority of respondents having attempted pregnancy reported infertility (69.4%); they were more likely to have seen a gynecologist first, although it is not known whether they were attempting pregnancy when they first sought care ($P = .0008$). Almost all respondents (98.9%) reported bowel symptoms, whereas only a third (34.7%) had urinary symptoms. Those seeing a generalist or other specialist first were more likely to report pain with urination over their lifetime ($P < .0001$). More than two thirds of respondents each reported having nausea/stomach upset or dizziness/headache during menses, with 48% reporting both. Those seeing a generalist first were more likely to have reported these systemic symptoms over their lifetime ($P < .001$ for all).

Except for infertility and painful urination, those with onset of symptoms during adolescence more frequently reported other symptoms over their lifetime (71.7% vs. 58.3% for all three pain types; 63.5% vs. 49.3% for heavy bleeding; 37.2% vs. 29.3% for premenstrual spotting; 99.4% vs. 97.5% for bowel symptoms; 55.2% vs. 34.0% for systemic symptoms; $P < .0001$ for all) than those with symptom onset as adults.

Diagnosis

Those having onset of endometriosis-related symptoms during adolescence more likely reported first seeing a generalist (adjusted OR = 1.31, 95% CI: 1.14, 1.51; $P = .0002$) (Table 2). Overall, the mean time from onset of symptoms to first seeking medical attention was 4.6 ± 0.1 years, with no statistically significant difference based on the first physician seen (Table 2). When age at onset of endometriosis-related symptoms was considered, women and girls who first experienced symptoms as adolescents waited three times as long (6.0 ± 0.2 years) as those with symptoms first as adults (2.0 ± 0.3 years) before seeking medical attention ($P < .0001$).

Once respondents sought medical attention for symptoms related to endometriosis, the mean time to diagnosis was another 4.7 ± 0.1 years, at an average age of 29.6 ± 0.1 years (Table 2). Whereas those first experiencing symptoms as adolescents, on average, had had diagnosis at a younger age than those whose symptoms began as adults (28.8 ± 0.1 years compared with 30.7 ± 0.1 years, $P < .0001$), adolescents waited longer from first seeking medical attention to receiving a diagnosis. That is, women and girls with symptoms beginning as adolescents averaged 5.4 ± 0.2 years from first seeking medical attention to diagnosis, compared with 1.9 ± 0.3 years for those who first experienced symptoms as adults ($P < .0001$). Those seeing a generalist first took longest to get a diagnosis (4.7 ± 0.2 years) compared with those seeing a gynecologist (3.6 ± 0.2 years, $P < .0001$) or other specialist (2.7 ± 0.5 years, $P = .0004$), even after adjusting for age and income (Table 2).

Most respondents (76.5%) saw fewer than five physicians overall before diagnosis. Not surprisingly, the time to diagnosis from first seeking medical care increased with the number of physicians seen: those respondents who received their diagnosis with the first or second physician seen averaged 1.7 ± 0.3 years, third or fourth physician averaged 4.2 ± 0.3 years, fifth through ninth physician averaged 7.3 ± 0.3 years, and those receiving their diagnosis after seeing at least 10 physicians averaged 8.8 ± 0.9 years to diagnosis ($P < .0001$). There was little difference with time to diagnosis among type of first physician seen (Fig. 1A), but a substantial difference by whether or not symptoms related to endometriosis first occurred during adolescence (Fig. 1B). Overall, respondents who first saw a gynecologist were more likely to see fewer physicians before diagnosis than those who saw a generalist or another specialist first ($P < .0001$) (Table 2). There was, however, no statistically significant difference in the age at diagnosis based on the number of different physicians seen.

TABLE 1

Demographic characteristics and reported symptoms by group of first physician seen among women with self-reported surgically diagnosed endometriosis who completed the 1998 Endometriosis Association Survey.

	Type of physician seen first			Total (N = 4,334) ^{a,c}
	Gynecologist, 50.3% (n = 2,180) ^{a,b}	Generalist, 45.1% (n = 1,955) ^{a,b}	Other, 4.6% (n = 199) ^{a,b}	
Age at survey ^d (y, mean \pm SE)	36.7 \pm 0.2	35.8 \pm 0.2	34.9 \pm 0.5	36.2 \pm 0.1
Race, % (n)				
White	94.7 (1,848)	94.1 (1,683)	93.2 (165)	94.4 (3,696)
Black	2.1 (41)	1.8 (32)	1.7 (3)	1.9 (76)
Hispanic	1.6 (32)	2.4 (42)	1.1 (2)	1.9 (76)
Asian	0.7 (14)	1.1 (19)	2.8 (5)	1.0 (38)
Native American	0.4 (7)	0.4 (7)	0.0 (0)	0.4 (14)
Other	0.5 (10)	0.3 (5)	1.1 (2)	0.4 (17)
Education, % (n)				
<High school	0.4 (8)	0.7 (13)	0.5 (1)	0.5 (22)
High school or other	8.8 (189)	11.0 (209)	10.2 (20)	9.9 (418)
College or beyond	90.8 (1,941)	88.4 (1,687)	89.3 (176)	89.6 (3,804)
Annual family income, % (n) ^d				
<\$50,000	31.9 (646)	41.2 (758)	37.9 (72)	36.4 (1,476)
\geq \$50,000	68.1 (1,381)	58.9 (1,084)	62.1 (118)	63.6 (2,583)
Lifetime symptoms, % (n)				
Pelvic pain ^d	97.8 (2,059)	99.1 (1,899)	98.5 (193)	98.4 (4,151)
Menstrual	82.6 (1,701)	85.2 (1,618)	83.4 (161)	83.8 (3,480)
Ovulatory ^d	73.6 (1,515)	78.0 (1,481)	75.1 (145)	75.7 (3,141)
Nonmenstrual ^d	69.2 (1,425)	75.1 (1,427)	75.1 (145)	72.2 (2,997)
All three pain types ^d	63.9 (1,316)	70.6 (1,340)	68.9 (133)	67.2 (2,789)
Heavy bleeding	57.2 (1,247)	60.2 (1,177)	56.8 (113)	58.5 (2,537)
Premenstrual spotting ^d	32.3 (704)	36.7 (718)	36.2 (72)	34.5 (1,494)
Infertility ^d	72.4 (994)	66.7 (734)	59.8 (64)	69.4 (1,792)
Urinary symptoms ^d	31.1 (593)	38.4 (664)	36.8 (67)	34.7 (1,324)
Bowel symptoms	98.7 (1,471)	99.1 (1,405)	99.3 (137)	98.9 (3,013)
Nausea/stomach upset ^d	65.5 (1,318)	72.6 (1,309)	68.8 (128)	68.9 (2,755)
Dizziness/headaches ^d	66.6 (1,328)	72.4 (1,291)	65.2 (120)	69.2 (2,739)

^a Total No. (denominator) may vary by question because of missing data.

^b Means \pm SE are least-squares (adjusted) means for main effects.

^c Means \pm SE are unadjusted.

^d $P < .01$ when groups of first physician seen were compared.

Greene. Diagnostic experience with endometriosis. *Fertil Steril* 2008.

The diagnosis of endometriosis was made by 69% of all gynecologists reported to have been seen but only 3.9% of generalists and 4.5% of other specialists.

Satisfaction With Medical Care

Almost two thirds (63.0%) of respondents were told nothing was wrong by at least one physician at some point while seek-

ing a diagnosis. Gynecologists made this remark more frequently (68.9%) than generalists and other specialists (52.9% and 13.4%, respectively). Sometime before diagnosis, women and girls who first experienced symptoms as adolescents were far more likely to report being told nothing was wrong than those whose symptoms began when they were adults (69.6% vs. 49.8%; adjusted OR = 2.26, 95% CI: 1.97, 2.59, $P < .0001$).

TABLE 2

Diagnostic process characteristics by group of first physician seen among women with self-reported surgically diagnosed endometriosis who completed the 1998 Endometriosis Association Survey.

	Type of physician seen first			Total (N = 4,334) ^{a,c}
	Gynecologist, 50.3% (n = 2,180) ^{a,b}	Generalist, 45.1% (n = 1,955) ^{a,b}	Other, 4.6% (n = 199) ^{a,b}	
Symptom onset and diagnosis				
Adolescent onset of symptoms, % (n)	64.3 (1,382)	70.9 (1,366) ^d	61.9 (120)	67.1 (2,868)
Adult onset of symptoms, % (n)	35.8 (769)	29.1 (561) ^d	38.1 (74)	32.9 (1,404)
Age at diagnosis, y (mean ± SE)	29.5 ± 0.11	29.3 ± 0.11	29.7 ± 0.36	29.6 ± 0.10
Time from onset of symptoms to seeking medical attention, y (mean ± SE)	4.0 ± 0.15	3.8 ± 0.16	4.1 ± 0.50	4.6 ± 0.10
Time from seeking medical attention to diagnosis, y (mean ± SE)	3.6 ± 0.15	4.7 ± 0.16 ^d	2.7 ± 0.49 ^e	4.7 ± 0.10
No. of physicians seen before diagnosis, % (n) ^f				
1–2	50.4 (1,030)	31.9 (589)	34.1 (62)	41.3 (1,681)
3–4	31.9 (652)	38.3 (707)	40.7 (74)	35.2 (1,433)
5–9	14.1 (289)	22.6 (416)	21.4 (39)	18.3 (744)
≥10	3.6 (73)	7.2 (132)	3.9 (7)	5.2 (212)
Satisfaction with medical care, % (n) ^g				
Not taken seriously overall	54.5 (1,097) ^e	65.8 (1,209)	53.5 (99) ^e	59.6 (2,405)
Found physicians helpful overall	55.8 (1,163) ^e	45.4 (849)	50.8 (95)	50.9 (2,107)

^a Total No. (denominator) may vary by question because of missing data.

^b Means ± SE are least-squares (adjusted) means for main effects.

^c Means ± SE are unadjusted.

^d $P < .001$ compared with group seeing gynecologist first; analysis adjusted for differences in age and income.

^e $P < .001$ compared with group seeing generalist first; analysis adjusted for differences in age and income.

^f $P < .0001$ by χ^2 test for trend for likelihood of gynecologist group seeing fewer physicians overall.

^g Taking everything into account while seeking a diagnosis.

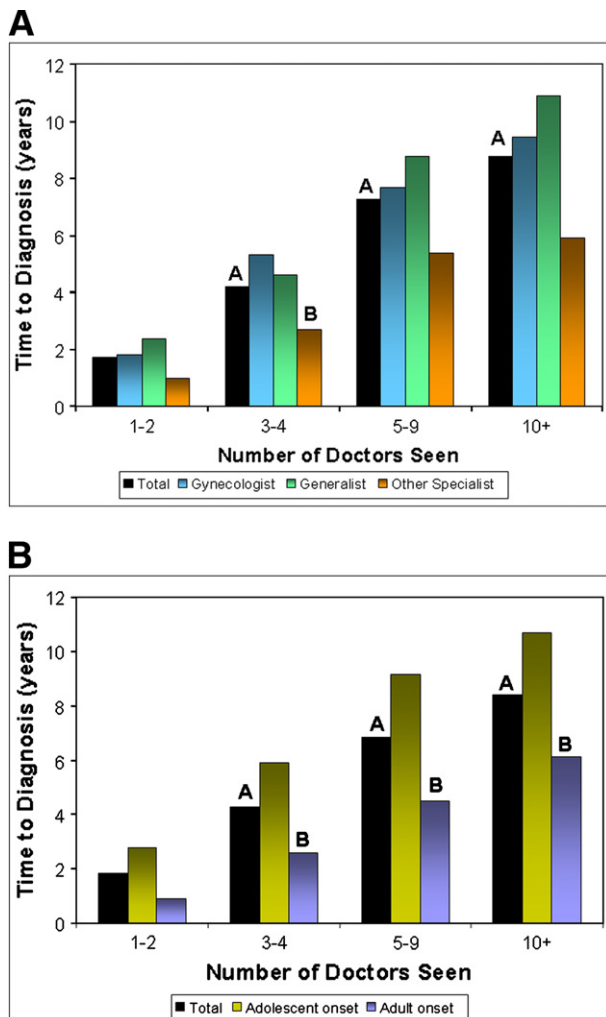
Greene. Diagnostic experience with endometriosis. *Fertil Steril* 2008.

Taking everything into account, more than half of the respondents (59.6%) reported that they were not taken seriously by their physicians overall. These respondents were more likely to have seen a generalist first compared with a gynecologist (adjusted OR = 1.60, 95% CI: 1.39, 1.83, $P < .0001$) or other specialist (adjusted OR = 1.80, 95% CI: 1.32, 2.47, $P = .0003$) (Table 2). They were also more likely to report onset of symptoms as adolescents than as adults (65.2% vs. 48.9%, adjusted OR = 1.95, 95% CI:

1.69, 2.24, $P < .0001$) if they reported not being taken seriously overall. Despite this, half (50.9%) reported their physicians to have been helpful overall during the diagnostic experience, especially if they had seen a gynecologist first compared with a generalist (adjusted OR = 1.48, 95% CI: 1.30, 1.69, $P < .0001$) (Table 2), or if they had onset of symptoms as adults rather than as adolescents (58.4% vs. 46.9%, adjusted OR = 1.59, 95% CI: 1.39, 1.82, $P < .0001$).

FIGURE 1

(A): Mean time to diagnosis from first seeking medical attention, by group of first physician seen. A: $P < .0001$ compared with 1 or 2 physicians; B: $P < .05$ compared with gynecologist group; adjusted for age and income and corrected for multiple comparisons. **(B):** Mean time to diagnosis from first seeking medical attention, by onset of symptoms. A: $P < .0001$ compared with 1 or 2 physicians; B: $P < .05$ for adolescent onset versus adult onset; adjusted for age and corrected for multiple comparisons.



Greene. Diagnostic experience with endometriosis. *Fertil Steril* 2008.

all before receiving a diagnosis, and gynecologists were by far the most likely specialists to diagnose endometriosis. Time to diagnosis was longest for those respondents who first saw a generalist. Seeing an increasing number of physicians was associated with increasing time to diagnosis, although this might mean that the diagnosis was elusive. Sometime before diagnosis, a surprisingly high proportion of women and girls reported having been told that nothing was wrong with them.

In the present study, the majority of respondents reported first experiencing symptoms as adolescents, and their diagnostic experience seemed much more difficult than for those women who first experienced symptoms as adults. Although endometriosis historically has been thought of as a disease that primarily affects adults, several studies have shown that it can affect young women (3, 16), including between 25% and 70% of adolescents with chronic pelvic pain (12, 13, 17). Each step of the diagnostic experience took longer for the adolescent-onset group: those first experiencing symptoms as adolescents waited over twice as long before seeking medical help and took longer to get a diagnosis once medical care was sought. They were also more likely to report not being taken seriously by their physicians overall or to be told that nothing was wrong, which reflects the previously reported findings that many physicians fail to consider endometriosis as a diagnosis in adolescents (12, 13) and likely helps explain the longer time to diagnosis.

A surprisingly large number of the respondents, including those whose symptoms began when they were adults, reported that their physicians had not taken them seriously overall or that they had been told that nothing was wrong sometime before diagnosis. This is consistent with the findings by Ballard et al. that part of the difficulty in diagnosing endometriosis may be due to the perception that the patient is not ill but that this perception is shared at least as much by the physicians as the patients themselves (11). The present study showed that the “delay” on the patient’s part (time from first experiencing symptoms to seeking medical care) was about equal in time to the delay once a physician became involved (time from seeking medical help to receiving a definite diagnosis of endometriosis). This is contrary to the study by Husby et al., which showed that the majority of the diagnostic delay was after the patient consulted a physician, with a mean time from onset of symptoms to seeking medical help of approximately 1.4 years and the time from seeking help to diagnosis of 5.2 years (18). It helps to keep in mind that patients, especially adolescents, may be dependent on their physicians (and their parents) to recognize they are ill and help them with their symptoms (17).

Many of the respondents in this study reported seeing several physicians before receiving a diagnosis, but, interestingly, three quarters saw fewer than five physicians. Not surprisingly, those who took longer to receive a diagnosis saw more physicians overall, perhaps not only because of a more complicated disease pattern, myriad symptoms, or presence of coexisting conditions but also simply because of physicians and patients not sharing a complete medical

DISCUSSION

Women and girls reporting surgically diagnosed endometriosis saw either a gynecologist or a generalist first in approximately equal proportions for their symptoms related to endometriosis. Almost all women and girls responding to the Endometriosis Association Survey reported pelvic pain, which commonly began during adolescence. Women and girls who saw a gynecologist first saw fewer physicians over-

history as a result of embarrassment, taboo, and stigma. Because the condition in the majority of women and girls reportedly was diagnosed by gynecologists, it is also not surprising that respondents who saw gynecologists first were more likely to see fewer physicians and receive a diagnosis faster than those who first saw generalists. In addition, gynecologists could perform a laparoscopy to diagnose endometriosis, whereas generalists cannot. However, it is less clear why the time to diagnosis from seeking medical attention was shortest for the women and girls who first sought medical care from another specialist. The smaller sample size ($n = 199$) relative to the other two groups may help explain part of the observed phenomenon.

The diversity of reported symptoms attributed to endometriosis over many years could well complicate the diagnostic experience, helping to explain the long time between seeking medical attention and diagnosis, as well as the number of physicians seen before a definite diagnosis. That the majority of respondents had gynecologic symptoms may explain why half of the women and girls saw a gynecologist first: 84% of respondents reported experiencing menstrual pain and 59% reported heavy bleeding, even though it is not known whether they had these symptoms when first seeking medical attention. Past studies have shown that the diagnostic experience is typically longer for those women experiencing pain symptoms as opposed to those experiencing infertility (5, 10). This may be supported by our observation that respondents with infertility were more likely to see a gynecologist first, which, in turn, was associated with seeing fewer physicians and a shorter time to diagnosis. However, the prevalence of both pelvic pain and infertility was very high in our study, and, given the cross-sectional study design, this survey did not establish the temporal sequence of symptoms in relation to the timing of seeking medical attention and obtaining a diagnosis.

In categorizing women and girls according to their age at first having symptoms and the first type of physician they saw, the assumption was made that women and girls in these groups would have similar experiences. Because this survey gathered information about the long-term health of women and girls who belong to the Endometriosis Association, it summarizes their recall of their health and experience during diagnosis. As a result, their completed surveys and this article express the impression of their experience—an experience that would be impossible to verify on such a large scale. Unknown are their financial resources and their access to expert medical care, which undoubtedly varies by region and whether they live in a rural or urban setting. In addition, the need for referrals to other specialists in the U.S. health care system may explain the large proportion of women and girls who first saw generalists, and the long time to diagnosis may be due, in part, to complications of insurance and referral patterns.

It is important to gather data directly from women themselves on their medical experiences. However, a different set of limitations related to recall and reporting errors, as well as interpretation of questions, may apply because of

the self-reported nature of the data for the present study. The data as made anonymous and deidentified also made it impossible to verify subject reports with medical chart reviews, although the qualitative information reported here may not be documented in medical charts. There may also be selection bias because the respondents included in our study were a highly educated self-selected group of women belonging to the Endometriosis Association. The characteristics of the study participants, therefore, may not be representative of the general female population or of all women and girls with endometriosis.

The cross-sectional study design, while providing valuable lifetime experience from thousands of women and girls, does not give a clear indication of the temporal sequence of events other than that specifically included in questions. It was also not possible to determine whether respondents seeing a generalist first did so merely for a referral for another specialist or sought a diagnosis from them because details related to the nature and purpose of each physician visit were not obtained. It is also important to note that certain analyses were found to be statistically significant because of the study's power to detect even minor differences, which may or may not be clinically relevant.

Despite the study limitations, the reported experiences of several thousand members of the Endometriosis Association provided useful information about the diagnostic experience of women and girls with pain and endometriosis. Only subjects reporting surgically diagnosed endometriosis were included, eliminating those with suspected but unconfirmed disease. The survey strived to be comprehensive, addressing some important questions related to the diagnosis of endometriosis. Adjustments for potential confounders that may affect the pattern of first physician seen were incorporated in the data analysis to minimize bias.

In conclusion, the study findings support our hypothesis that women and girls who see a gynecologist first for symptoms of endometriosis are more likely to report a shorter time to diagnosis, see fewer physicians, and report a better experience overall with their physicians during their diagnostic experience. Despite this, sometime before diagnosis, a surprisingly high proportion of respondents reported having been told by gynecologists that nothing was wrong with them. We also observed a very high proportion of women and girls reporting onset of symptoms during adolescence, who in general reported a longer time to diagnosis and a worse experience with their medical care while obtaining a diagnosis. These findings shed new light on the types of challenges women and girls face while seeking medical care for endometriosis, and potentially identify areas of improvement from the physician's perspective, as well as from the patient's.

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